The forgotten people: survey of the chronic younger sick in Welsh hospitals[1]

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Summary: In a survey of Welsh hospitals, 96 patients were identified who had been continuously resident for between 4 months and 20 years; they were aged between 15 and 65 years on admission. The commonest causes for such admissions were cerebrovascular accidents, trauma and diabetes. Suitable facilities for the long-term care and rehabilitation of such severely disabled young people are very limited in Wales, and in an era when rehabilitation should be possible they have been forgotten.

Introduction

All clinicians are well acquainted with the problem of the young patient who is admitted as an acute emergency and subsequently develops severe disability following a stroke or road traffic accident. There are, of course, other causes for severe disability. In a certain percentage of these patients the disability is such that they are never likely to return to the community and live an independent existence. Some would argue that all disabled patients should be returned to the community, but in this study we have identified a substantial group of people who have become long-term residents of acute hospitals. There is clearly a need for care and rehabilitation facilities, but at present many of these patients are forgotten people who fall outside the remit of government and voluntary social services.

Methods

A simple questionnaire about long-stay patients in Wales was sent to all consultants in general medicine, rheumatology, dermatology, geriatrics and orthopaedic surgery. They were asked to provide details of age, duration of stay and cause of admission of all patients who, on 31 December 1982, had been continuously resident in hospital for 4 months or longer and who were aged between 15 and 65 years on admission. No attempt was made to identify long-stay patients from Wales who were in hospital outside the principality; nor were patients' names and addresses requested on the questionnaire. In Wales, paediatricians care for children up to the age of 13 years and were not included in the survey.

Results

Of the 185 questionnaires distributed, 154 replies were received (83% response rate) which identified 96 patients who had been continuously resident in hospital for more than 4 months; 56 were men and 40 women with age distributions as shown in Figure 1. Men had been resident for an average of 26 months, with some as long as 20 years (Figure 2). Women had been resident for an average of 28 months. The longest stay by any woman was 10 years.

Cerebrovascular events such as strokes and subarachnoid haemorrhages accounted for 42 of the 96 admissions (Table 1). Multiple sclerosis was responsible for 10 long-term admissions and the effect of diabetes for 5. Ten patients were present in hospital as a result

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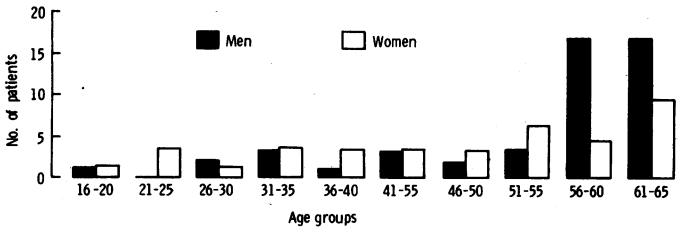

Figure 1. Age of 96 chronic young sick patients on admission to hospital

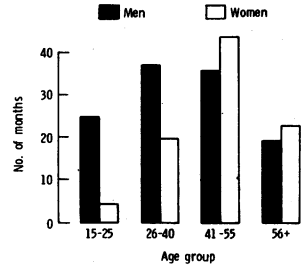

Figure 2. Mean duration of stay of chronic young sick patients by age group

of trauma usually sustained in a road traffic accident. Other causes of prolonged admission included myotonic dystrophy (1), Guillain Barré syndrome (1), Parkinsonism (2), spina bifida (3), familial ataxia (1), bullous pemphigoid (1) and the sequelae of herpes encephalitis (1).

Discussion

The subject of the long-stay young patient in hospital is an emotional issue which confronts most hospital practitioners. Acute medical and surgical wards are not suitable either for the rehabilitation of the severely disabled or for the continued care of the chronically sick. In general, the nursing and medical staff of these wards are not trained to assess the physical and psychological needs of the disabled; physiotherapists and specialized occupational therapists often have insufficient time to spend with individual patients and the atmosphere of the ward is directed towards an early return home.

In 1971, Harris *et al.* estimated that there were 14 000 severely handicapped people living at home in Wales (a prevalence of 285/10 000 population). Many of the patients were bedfast and required considerable help, but they are distinct from those who have become permanent hospital residents. In this survey we identified 96 adults who were in hospital for more than 4 months (Table 2). Paediatricians in Wales generally manage children under the age of 13 years. As their patients have not been included in this study, it is likely that our figures represent an underestimate of the extent of the problem.

In practice, first-time acute ward admissions that result in a long stay reduce the opportunity of a patient finding suitable accommodation in the community or of being admitted to effective rehabilitation programmes. Such patients are given a low priority by the staff of social service departments, who believe that they are already in receipt of some form of care. In a society which is now more conscious of the needs of the disabled, the long-term hospital patient has truly been forgotten.

Prior to hospitalization most of these patients were not disabled and their chronic disability is the result of the acute episode that led to their initial admission into an acute ward. The reasons for their failure to return to their previous environment include: their dependence on intensive nursing procedures which may include total respiratory

Table 1. Cause of admission of 96 patients, aged 15–65, who had been resident in hospital for at least 4 months on 31 December 1982

	Male	Female	Total
Strokes and subarachnoid haemorrhages	28	14	42
Multiple sclerosis	5	5	10
Diabetes	4	1	5
Trauma	6	4	10
Other	13	16	29
Total	56	40	96

Table 2. Distribution of chronic young sick in Welsh hospitals ●

Area	Geriatric wards	Identified from HAA	This survey
South Glamorgan	25	62	20
Mid-Glamorgan	13	65	21
West Glamorgan	0	41	7
Gwent	6	54	19
Dyfed	3	25	13
Powys	2	10	1
Gwynedd	7	12	4
Clwyd	3	26	11
Wales total	59	295	96

● Identified from the statutory annual report of young patients in geriatric beds, data collected by Hospital Activities Analysis (HAA) and in this survey

dependence, the need for parenteral or nasogastric or gastrostomy feeding, the need for faecal and urinary control, or problems of communication as well as the less intensive problems of hygiene and skin care. The level of care required militates against their return to a home environment and often to any specialized long-stay colony or village. Apart from the intrinsic problem of the individual patient, there may also be a problem occasioned by interactions with other members of a long-stay community.

Ideally even the severely disabled should be cared for in a community, but there are patients – as shown in this study – who require greater care than is at present available outside a hospital. With this in mind, some workers have attempted to calculate the number of beds required by any given population to provide adequate facilities for the severely disabled. Work by Maddocks (1976) in South Glamorgan has shown that there is a need for between one and two beds per 10 000 population, and at such a level there would also be provision for holiday relief accommodation. These findings are very similar to those reported by Williams & Lambourne (1973) using a theoretical model.

The simple recognition of long-stay patients will not resolve the problems with which they are associated. In an ideal world it may be possible to care for all such patients in the community, but in practice this does not occur. In Wales official support and encouragement of Family Support Units is lacking. Such units would enable the families of potentially long-stay patients to care for them in their own homes. The purchase and supply of specialized equipment and the adaptation of a patient's home would be major capital costs. Professional advice and support from appropriately trained physicians, nurses and physiotherapists and other specialized paramedical disciplines must be readily available to allow such concepts to function efficiently and to ensure that the patient does not suffer. Family support units will need local hospital-based centres to provide care if the family's support fails for any cause.

For some patients the only practical form of care is hospital-based. The establishment of special units for these patients will bring with it the problem of difficulty in visiting; such specialized units should be sited within the boundaries of the district general hospital – not as an isolated unit, but as a unit of the normal medical and nursing work and training programmes. The consultant in charge of such a ward would, perhaps, best be a physician with a special interest in rheumatology and rehabilitation, but who would have had training in the mobilization and utilization of both welfare and voluntary services, and whose work might entail visiting patients isolated in other hospitals in the region and also providing the medical expertise required by severely disabled patients nursed at home. Such a service would enable these patients to receive facilities which are available to some patients in the community, but not necessarily to those in hospital. Such a unit could be the centre of training for medical and nursing staff at all levels of seniority.

The improvement of facilities and the rehabilitation of these severely disabled patients depends on the recognition of the scope of the problem, and we hope that this short paper will encourage some thoughts on the 'forgotten people'.

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